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ABSTRACT

The report presents and discusses the recommendations for executive or legislative action made by the President's Task Force on the Mentally Handicapped, after having reviewed existing programs, both public and private. The recommendations concern both the mentally retarded and the mentally ill. The major areas covered are prevention, treatment and short-term care, rehabilitation and extended care, social problems, financing mechanisms and the organization and delivery of services, research, manpower and training, and public attitudes and public education. (KW)

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ACTION AGAINST MENTAL DISABILITY



The Report of
The President's Task Force on the
Mentally Handicapped
September, 1970

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The President's Task Force on the
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THE PRESIDENT'S TASK FORCE
ON
THE MENTALLY HANDICAPPED

May 28, 1970

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EXECUTIVE SECRETARY

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

On behalf of The President's Task Force on the Mentally Handicapped, I am pleased to send you the attached copy of our report.

We are conscious that, in the comparatively short time allotted to us, we could not deal exhaustively with the important issues that come within the scope of our charge, but we believe that our recommendations cover the principal long- and short-term needs of the mentally disabled.

We desire to thank the numerous organizations, Federal program leaders and other individuals who have given us information and advice.

We also wish gratefully to acknowledge the work of our Executive Secretary, Dr. Bertram S. Brown, who arranged our meetings and organized the drafting of the report.

To you, Mr. President, we wish to express our gratitude for enabling us to show our deep sense of personal commitment in advising you how the mentally disabled may, with the rest of our citizens, enjoy a better quality of life.

Respectfully yours,

Jeannette Rockefeller
Jeannette Rockefeller

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DECEMBER 18, 1969

The White House

The President today announced another of the task forces that are being established to assist the Administration with ideas and recommendations for 1970 and beyond. Mrs. Winthrop Rockefeller, member of the President's Committee on Mental Retardation and highly respected by those involved in the fields of mental illness and mental retardation, will serve as Chairman of the Task Force on the Mentally Handicapped.

The Task Force will review existing programs, both public and private, and make recommendations designed to improve both services and opportunities.

The members of the Task Force on the Mentally Handicapped are:

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New York, New York

Recommendations

Long-term

Rec. 3 (Page 22)

The Task Force recommends that prenatal and perinatal services such as those offered in the Maternal and Infant Care projects be made available to all who need them. These should include the newer diagnostic, interventive, and preventive techniques.

Rec. 4 (Pages 22-23)

The Task Force recommends that a system of universally available day care programs, from infancy to school age, be established under a variety of aus-

Short-term

Rec. 1 (Pages 14-16)

The Task Force recommends the establishment, under both executive and legislative auspices, of a Joint Council on Disabilities that would bring together and direct the advocacy and review functions of the existing President's Committee on Mental Retardation and two new committees: a President's Committee on Mental Health and Illness and a President's Committee on Physical Disabilities.

Rec. 2 (Pages 20-21)

The Task Force recommends that the government provide active leadership for increased support of birth control research, increased dissemination of birth control information, and increased availability of birth control measures and voluntary sterilizations and abortions.

Long-term

pices. These programs should involve the children's families, collaborate with health, mental health, educational, and social services, and provide continuity at school age with the services of the regular school.

Rec. 5 (Page 23)

The Task Force recommends the expansion of programs to detect problems of social adjustment and intellectual competence in preschool and primary-grade children. Early individual management of these problems should be provided.

Rec. 6 (Pages 24-25)

The Task Force recommends two simultaneous approaches to better informed parenthood:

(a) *Parental Education*—An effort to provide family-life and health information to young parents through such means as well-baby clinics, public and private social agencies, public school, adult education courses, and the educational campaigns of community mental health centers;

(b) *Education for Parenthood*—A curriculum on parenthood, and family life, including health measures, to begin in the elementary grades and continue through high school at least.

Rec. 9 (Pages 28-29)

The Task Force recommends the establishment of community-based geriatric programs, each serving a defined

*Short-term***Rec. 7 (Pages 26-27)**

The Task Force recommends expansion of programs and facilities for the diagnosis, treatment, and rehabilitation of the mentally retarded. The need for expanded community services and improved institutional programs leads the Task Force to recommend legislation that will assist the States and communities to carry forward the State comprehensive mental retardation plans initially developed during the late sixties.

Rec. 8 (Page 27)

The Task Force recommends the continued expansion of comprehensive community-based programs, with new emphasis to be given to developing within these programs special efforts to deal with the mental health problems of children and youth, including the abuse of drugs and alcohol.

Rec. 10 (Pages 29-31)

The Task Force recommends a substantial increase in Federal resources to support research, training, commu-

Long-term

geographical area and providing diagnosis, short-term treatment, and placement. Though separately funded and staffed, these should, wherever possible and appropriate, be affiliated with a comprehensive health center and include psychiatric consultation services. In other facilities and programs now caring for the aged, adequate health care and psychiatric consultation services must be available.

Rec. 11 (Page 31)

The Task Force recommends that steps be taken to encourage employers, organized labor, and government to collaborate in the planning and provision of treatment, rehabilitation, and prevention services for workers with mental disabilities and their families.

Short-term

nity-based treatment facilities, and public education to combat two major problems affecting our national health—drug abuse and alcoholism.

Rec. 12 (Pages 31–33)

The Task Force recommends that special educational services, now reaching less than one-half of the children who need them, be made available, in the public schools and residential institutions, for all disturbed and retarded children.

Rec. 13 (Pages 34–35)

The Task Force recommends the immediate improvement of institutional services and the setting of minimum quality standards. Specifically, it recommends that the Hospital Improvement Program and the Hospital Inservice Training Program for the mentally ill and the mentally retarded be given increased resources.

Rec. 14 (Pages 35–36)

The Task Force, commending the State-Federal program of vocational rehabilitation for its successful efforts to help disabled people lead independent lives, recommends increased support of the program at both Federal and State levels.

Rec. 15 (Page 36)

The Task Force commends the work of the President's Committee on the Employment of the Handicapped and recommends that an even greater na-

Long-term

tional effort be made to publicize the needs of the mentally disabled for employment and their value as employees.

Rec. 16 (Page 39)

The Task Force acknowledges the needs of the criminal justice system in coping with the problem of crime; at the same time, it recommends that the Administration give increased emphasis to crime and delinquency as a mental health problem.

Rec. 17 (Page 40)

The Task Force recommends that high priority be given to means of ensuring special attention for mentally ill and mentally retarded offenders at all points in their dealings with the mental health and criminal justice systems. This would be an appropriate subject for consideration by the Joint Council on Disabilities.

Rec. 18 (Pages 40-41)

The Task Force recommends that the laws concerning the mentally ill and the mentally retarded be reviewed and that model mental health and mental retardation acts be prepared for consideration by the State legislatures. The Joint Council on Disabilities would be particularly qualified to sponsor this activity.

Rec. 20 (Page 44)

The Task Force recommends that a special study of the administrative relationships among Federal, State, and local governments in the field of mental disability be undertaken and that recommendations for their improvement be made. This would be an appropriate undertaking for the Joint Council on Disabilities.

*Short-term***Rec. 19 (Page 43)**

The Task Force recommends that, as block grants develop, special provision be made for a distinct allocation for the programs that involve the mentally disabled.

Rec. 21 (Pages 44-45)

The Task Force recommends that the National Institute of Mental Health continue as a unified comprehensive operation containing research, training, and services, and that it not be fragmented or altered but rather strengthened in its ability to relate and coordinate its efforts with health and social problems.

Rec. 22 (Pages 45-46)

The Task Force recommends that the Secretary of Health, Education, and

*Long-term***Rec. 23 (Pages 45-46)**

The Task Force recommends that the Joint Council on Disabilities in conjunction with the appropriate Secretaries review the organization of mental disability services at the inter-departmental level and recommend needed improvements.

Rec. 26 (Page 49)

The Task Force recommends that the Federal Government officials most closely concerned with programs for the mentally disabled keep in close touch with the national health insurance field in order to make sure that appropriate provisions for the mentally disabled are included in any program for universal health care financing.

Rec. 27 (Page 49)

The Task Force recommends a special study of the total financing of programs for the disabled, including both public and private sources. A continuing mechanism should be developed so that financial data are available to program leaders at Federal, State, and local levels as well as to organizations in the private sector. These would be

Short-term

Welfare review the organization of mental retardation services within the Department of Health, Education, and Welfare and establish some mechanism for more effective coordination and greater visibility.

Rec. 24 (Page 47)

The Task Force recommends that the Federal Government initiate an immediate program to train State and local government officials in the planning and administration of programs for the mentally disabled.

Rec. 25 (Pages 47-48)

The Task Force recommends that all provisions discriminating against the mentally disabled be removed from Medicare and Medicaid laws, regulations, and administration; further, that the government develop and promote legislative and administrative measures to enhance the capacity of the service system.

Rec. 28 (Pages 50-51)

The Task Force recommends increased funds for research into the causes and treatment of mental illness and mental retardation. With respect to mental retardation, it recommends specifically that adequate support be provided for the mental retardation research centers that have already been constructed with Federal funds.

Long-term

appropriate concerns of the Joint Council on Disabilities.

*Short-term***Rec. 29 (Page 51)**

The Task Force recommends that the Office of Education give strong attention to the issues of learning disability, the biomedical aspects of learning, and the education of the emotionally ill, mentally retarded, or otherwise disabled youngster.

Rec. 30 (Pages 51-52)

The Task Force recommends that a significant increase in resources be made available for biometric and epidemiological research purposes in the field of mental disability.

Rec. 31 (Pages 53-54)

The Task Force recommends that funds be made available at the levels originally planned to meet the staffing needs of the mental health and mental retardation centers. It draws specific attention to the training funds administered by the National Institute of Mental Health and to those needed for the operation of the University Affiliated programs. It also draws attention to those for the training of special education personnel. Also in the area of the University Affiliated Facilities, it urges that plans be made to increase the current 20 centers to the original goal of 60.

Rec. 32 (Pages 54-55)

The Task Force recommends that the President appoint a committee to consider a proposal for an academy of human services.

Rec. 33 (Pages 55-56)

The Task Force recommends that a Presidential committee study the desirability and feasibility of establishing a universal public service system. The

Rec. 34 (Page 57)

The Task Force recommends that the national effort to increase voluntarism include provisions for determining a community's need for volunteers and

Long-term

basic idea to be thoroughly explored is that all Americans, probably beginning somewhere between the ages of 17 and 19, serve their country for two years in one of a variety of areas, including the military and the health and social welfare programs of the private and public sectors.

Rec. 35 (Pages 61-62)

The Task Force recommends that each of the committees of the Joint Council on Disabilities review the subject of public attitude. The Joint Council should then recommend overall policy for improving the public attitude towards mental illness, mental retardation, and physical disability.

Short-term

for recruiting, screening, placing, training and supervising volunteers.

CHAPTER I

Introduction

President Nixon charged us, a group of citizens, to review the field of the mentally handicapped and make recommendations for legislative or executive action for 1970 and ensuing years.

We were excited and challenged by the assigned mission of providing a needed overview of the mentally ill and the mentally retarded in order to determine how they could achieve maximum independence, security, and dignity. Specifically, we were asked "to review what the public and private sectors are now doing for mentally and emotionally handicapped Americans, and to recommend what would be done in the future."

The size and scope of the problem of mental disability warrants a cogent national strategy. It is estimated that some 20 million Americans could benefit from mental health services and that 3.5 million receive care for mental illness in the course of a year. The resident population of public hospitals for the mentally ill numbered about 367,000 in 1969.

Mental illness costs more than \$20 billion a year. This includes more than \$4 billion for treatment and preventive services—by Federal, State, and local governments and by private agencies and individuals. It includes also about \$16 billion in economic losses caused by inability to work, excessive absenteeism, and other such factors.

About 6 million Americans are mentally retarded. On average, 215,000 are in institutions at any one time and 690,000 are attending special classes.

The cost of mental retardation comes to about \$8 billion a year. Included are \$2.5 billion for residential treatment, special education, and clinical and rehabilitation services, and \$5.5 billion for loss of earnings.

In both cases, losses chargeable to premature deaths, to the criminal activities of drug addicts and other disturbed individuals, and to pain, frustration, and other intangible factors that seriously reduce the quality of life, for both those with mental disabilities and those close to them, are not included.

Operating as a Task Force, we have had six meetings over a total of eleven days during the months of January to April, 1970.

In addition to our own discussions, we have met with the key Federal program leaders in the field, and we have asked for and received information and advice from many organizations and individuals con-

cerned with the mentally retarded and the mentally ill. For this rich material we express our gratitude.

In the following chapters we try to give a condensed yet reasonably comprehensive view of the various aspects of what is at once a fight against mental disability and a struggle for quality of life. The summary offers a quick look at our major findings; the body of the report presents in more detail the facts and the reasonings that led to them. By "long-term" recommendations we mean proposals that can be made effective only over a period of several years, though studies and planning for them can be started now; by "short-term," proposals that can be made effective in a matter of months.

CHAPTER II

Definitions

Society has always distinguished between the mentally ill and the mentally retarded: paired but distinct terms such as "madmen" and "fools," "lunatics" and "idiots" have been handed down in common parlance and legal history from the earliest times. The main basis for the distinction was that the "idiot" was presumed to be incurable whereas the "lunatic" might be expected to recover his sanity or at least to have lucid intervals. It was also generally held that the impairment associated with retardation was present in early childhood and persisted throughout the individual's life whereas the symptoms of mental illness, which showed a natural tendency to remit, usually occurred in adult life in persons who had previously functioned normally.

Advances in knowledge of causation, management, and specific treatment have shown that these distinctions are far less sharp than was originally supposed. Both mental illness and mental retardation may have physiological or socioenvironmental causes, or both. Also, the retarded child, struggling with his environment, may become psychotic; the psychotic child may develop grave learning problems.

A system of classification of mental disability is essential for diagnosis, for epidemiological purposes, and for international communication. But because mental disability presents so few objective diagnostic criteria, either in the field of mental illness or of mental retardation, classification is mainly based on symptoms and the little that is known of biological causes. *A serious practical disadvantage of this system is that it has led to the "labeling" of individuals in terms that only too often suggest an unmodifiable disease process or basic constitutional deficiency and therefore a discouraging end state, and to the provision of services in keeping with the label rather than with the needs of the individual. The Task Force wishes to emphasize that current thinking attaches at least as much weight to the socioenvironmental as to the biological components in the etiology of both mental illness and mental retardation.*

"MENTALLY DISABLED"

The basic issue of definition arose at the very start of Task Force deliberations, in connection with the term "handicapped." As an ana-

logue to "physically handicapped," the Task Force was aware of the genesis and rationale for the term "mentally handicapped." However, both among its members and its outside advisors, it found that the term did not encompass adequately its concerns or its charge covering the broad fields of mental health and mental retardation. *Task Force concerns range from people who are acutely disturbed for a brief period of time to people who are severely handicapped for their full life span.* The members were also aware that inappropriate and unnecessary "labeling" may itself be harmful.

Fully cognizant of the difficulty of finding any term that could satisfy the demands of public communication and professional validity, the Task Force finally decided to use the term "mentally disabled." It was selected as a substitute for "handicapped" because mental illness need not be a permanent handicap and because modern concepts of mental retardation are moving towards the view that some retarded individuals need not be handicapped through their full life span.

MENTAL RETARDATION

Until fairly recent times, mental retardation was thought to be an unmodifiable condition caused solely by hereditary influences or by brain damage associated with infections or intoxication, disorders of metabolism or nutrition, birth injuries, or prematurity. Research was devoted largely to exploring how these factors arose and operated and how they might be prevented. Persons with an intellectual deficiency correctly ascribed to one of those factors constitute a relatively small section of the mentally retarded population. They are, however, the most severely affected and have the least likelihood of being assisted to a fully independent life.

The picture of mental retardation as a static, unmodifiable condition was strengthened by the widespread practice of classifying and labeling individuals in terms of intelligence quotient, or I.Q. The adoption of this method of classification has done much to hinder progress in the understanding of mental retardation. Its legal acceptance has condemned innumerable individuals to institutions for life and at the same time has neglected many other individuals who, despite a normal I.Q., have been unable to function appropriately because of emotional immaturity, learning disorder, or other disability. It is now generally recognized that a deficiency in intelligence as measured by I.Q. tests should not be in itself a criterion of mental retardation in the legal sense, for many individuals in this category are self-supporting in the community and mentally healthy.

The greater part of those described as mentally retarded, it is believed today, have suffered from developmental difficulties associated with social and environmental deprivation. The probability of a rapid return from research and the opportunity for immediate social and education intervention both in prevention and treatment are greater with this group than with the more severe categories where the impairment is more clearly biologically caused.

MENTAL ILLNESS

Although the classification of mental illness is usually based on symptoms, etiology, and outcome, no entirely satisfactory and comprehensive definition of the term exists. Legal definitions vary from State to State and, in any case, are mainly concerned with the identification of the relatively small number of severely ill persons who are incompetent to manage their own affairs and from whom society may need to be protected.

Until very recent times the incidence of mental illness in a population was equated with the first admissions to a mental hospital, and the prevalence was estimated in terms of the number of patients the hospitals contained. These indices no longer have any general validity.

In the search for the causes of mental illness, structural changes in the brain have so far been identified in only a minority of disorders, notably those associated with infections, intoxicants, tumors, vascular disease, and changes due to the aging process. However, research into brain function in the disciplines of neurophysiology and biochemistry has made enormous strides and, by discovering biological concomitants, may well introduce radical changes in the definition, classification, and treatment of mental disorder.

In spite of great deficiencies in scientific knowledge, the last 30 years have seen a revolution in the methods and effects of psychiatric treatment. This movement, which already has reduced substantially the number of patients in mental hospitals, owes as much to a change of attitude towards the mentally ill as to advances in their treatment. A more humane and liberal approach not only has led to earlier and consequently more effective treatment but also has modified the forms of the illnesses themselves, so that the gross abnormalities of behavior that formerly were the hallmark of mental illness and a basis for classification are becoming rarities.

In no other field of health is the interplay of heredity, development, and environment so necessary to understanding as in mental illness. *In this connection the Task Force again expresses its belief that social and*

environmental deprivation plays a crucial part in the origin and perpetuation of many forms of mental disability. The Task Force points to the role of faulty development in early childhood in causing mental disturbance later in life, and to the influence of learning difficulties on both the emotional and the intellectual development of children. It emphasizes that parental neglect, lack of intellectual and emotional stimulation, and physical abuse of children are commonly associated with emotional disturbance, school failure, and even violence later on, and that these faults in upbringing can be found in every social class. It stresses the relationship between mental illness and the strains imposed by poverty and bad housing, whether in crowded urban or depressed rural areas. And it recognizes the contribution that these conditions make to the growth of social deviance in the form of racism, violence, delinquency, drug abuse, and alcoholism.

CHAPTER III

A National Strategy

The appointment of a task force on the mentally handicapped indicates the President's commitment to enhance the quality of life of all our citizens, including our most unfortunate and least privileged. The members of the Task Force feel that its establishment by the President and subsequent action on this report will promote significantly public understanding of the problems of mental disability and thus improve the well-being not alone of those with disabilities but of all of us.

As already stated, mental illness or mental retardation affects some 26 million Americans and costs the country at least \$28 billion a year. A comprehensive, national strategy that would implement our concern for this large number of mentally disabled citizens must include expansion and improvement in four major areas: First, prevention, to reduce the incidence; second, treatment and short-term care, to bring health and maximum social competence as soon as possible; third, rehabilitation and extended care, to enable the disabled to live useful and satisfying lives; and last, research, to increase knowledge that will improve programs in all these areas. Basic to all four areas is competent and adequate manpower.

A JOINT COUNCIL ON DISABILITIES

The Task Force has been especially concerned with the absence of any focal point where the needs of the mentally disabled can be viewed as a whole and where national policy can be formulated and national goals laid down.

***Rec. 1.*—The Task Force recommends the establishment, under both executive and legislative auspices, of a Joint Council on Disabilities that would bring together and direct the advocacy and review functions of the existing President's Committee on Mental Retardation and two new committees: a President's Committee on Mental Health and Illness and a President's Committee on Physical Disabilities.**

The proposed Joint Council on Disabilities could well function under the Administration's new Domestic Council.

The present lack of a national vantage point for viewing problems associated with mental disability leads to fragmentation of policymaking

and funding and to gaps, overlaps, and lack of continuity in State and local services. The Joint Commission on the Mental Health of Children, which was authorized and supported by Congress and has just completed its three-year work, points to this defect in the case of services for children; it is equally evident in the field of mental retardation, where it may reflect the growth of the specialty from its largely static concern with biological origins to its present dynamic concern with education and sociology.

In considering remedies for this situation, the Task Force noted that mental retardation affects people of all ages, cannot be entirely separated from mental illness, and may be associated with physical disabilities. Its service and research needs, like those of mental illness and physical disability, include the whole range of the biological and social sciences. The Task Force noted further that the physically disabled often have to struggle with emotional and mental problems. The conclusion followed: *Any integrative mechanism will have to be concerned with all three elements. It should represent the physically disabled as well as those suffering from disabilities associated with mental illness and mental retardation.*

In reaching this conclusion, members of the Task Force were well aware that the traditional separation of mental illness and mental retardation has been a barrier to collaboration between workers in these areas. The experience of working together as a group, however, has convinced the Task Force members that a joint approach to these problems is not only entirely possible but also highly desirable, indeed essential.

The Task Force believes that a coalition of constituencies will give each one of them greater weight and that the very existence of the Joint Council on Disabilities will ensure Presidential and national commitment. At the same time, the Joint Council will simplify and facilitate the executive and legislative operations necessary in discharging national responsibilities for people with disabilities of any nature. For example, the Joint Council could help to potentiate and implement the excellent report, *MR 69*, produced by the President's Committee on Mental Retardation. The Task Force not only endorses this report but has sought ways in which the recommendations could be implemented.

The success of the President's Committee on Mental Retardation in focusing attention on the problems and the opportunities for service in this field suggested the formation of analogous committees for the mentally ill and the physically disabled, with the three bodies being linked by the recommended Joint Council. The desirability of Presidential committees, with their concern for activities in both governmental and private fields, is especially great in the case of mental illness, where the

major services are shifting to a community base. In the interest of visibility and effective advocacy, it was evident that the Joint Council must have access to the President, the Congress, and the Public.

In order to retain the autonomy of its major constituents, the Joint Council should be a superordinate body integrating the work of three committees of equal size representing the mentally ill, the mentally retarded, and the physically disabled.

Each committee should consist of some 20-30 members covering public, private, and professional interests. The three committees should be called: The President's Committee on Mental Health and Illness, The President's Committee on Mental Retardation, and The President's Committee on Physical Disability.

The Council should comprise 21 members—five elected by each of the three committees from its membership and six, from outside the committees, appointed by the President. The Joint Council would steer the work of the committees and make recommendations to the President and the Congress.

The Joint Council on Disabilities should advise the President and the Congress on current and proposed programs affecting people with disabilities, and it should develop policy relating to standards, quality control, and evaluation.

Throughout the deliberations of the Task Force the need to establish standards and to evaluate Federal, State, and local programs was a consistent theme. Without these checks there can be no guarantee of efficiency or a logical basis for funding. However, no agency can be expected to perform an unbiased evaluation of its own functions or of the services it controls. While the Joint Council on Disabilities should set standards, the actual work of evaluation should be undertaken by a professional group that is not associated with the agency administering the program to be evaluated and preferably is independent of the Federal Government.

In order to fill its critical role, the Joint Council will require a variety of sources of information ranging from biometric statistics to the results of specific studies and surveys that it should be in a position to initiate. It should establish close liaison with such related agencies as The Presidents' Science Advisory Committee and The President's Committee on Employment of the Handicapped and with such program area councils as the National Advisory Council on Education of the Handicapped, the National Advisory Mental Health Council, and the National Advisory Child Health and Human Development Council.

The Joint Council and the President's committees should be provided with an adequate staff and budget.

INTERNATIONAL RELATIONS

The problems of mental disability are worldwide and affect all nations. This common vulnerability can be used to bring nations together.

Significant advances in programs against mental disability have already been made through the exchange of experience. For example, the open hospital movement in the United Kingdom is now having, 10 years later, a strong impact in the United States. The good effects of dividing large hospitals into autonomous units were first described in France; the practice has since spread to the United States and the United Kingdom. And Denmark has made a significant contribution to the architectural planning of community residential facilities for the retarded.

The "international bill of rights for the retarded" is used by many countries and some of our States as a basis for improving services to the mentally retarded. Partnerships of United States and South American professionals, volunteers and parents of the mentally retarded provide a new and unusual form of mutual cooperation in which governments are helpful bystanders instead of principal parties.

The oldest and some of the newest psychotropic drugs were found and first used by foreign scientists and clinicians. Studies of genetic factors in mental illness have been greatly facilitated by the excellence of medical records in Scandinavian countries. Many of the issues that have been discussed by the Task Force—social problems, for example, alcoholism, drug abuse—are already the subject of international cooperation. The need for establishing the types and distribution of mental disability in different populations has led to the search for international agreement on classification and terminology and also to research on cultural differences among nations. All this is essentially an exercise in international communications. In the long run it will advance knowledge of the causes of mental disability and more immediately it will increase international understanding.

The Task Force recognizes the field of mental disability as one of common, international concern in which a dynamic perception of the similarities among nations is likely to be more profitable than a static acceptance of the differences. *It calls for an increase in the opportunity for the international exchange of scientific information on mental disability both for its value in advancing knowledge of the problem and as a means of promoting a better understanding among nations.*

CHAPTER IV

The Prevention of Mental Retardation and Mental Illness

By proverbial wisdom and common sense, prevention of disability is greatly to be preferred to treatment and rehabilitation. Preventive measures, however, can be only as successful as the information underpinning them is sound and adequate. In the past, research efforts yielding new knowledge with resultant preventive possibilities have had a high payoff and they promise an even higher one in the future. A commitment to prevention is the best argument for support of research.

Opportunities for prevention cover the entire life span and involve many areas of action. All are important not only because they prevent human suffering but also because they offer a very considerable economic saving for a comparatively modest outlay. The current rubella vaccination campaign, for example, will prevent in the years to come thousands of cases of mental retardation, and the accompanying losses of millions of dollars in earning power, sometimes caused by damage to the fetus when the mother has rubella during pregnancy. (The 1964 rubella epidemic resulted in an estimated 20,000 children born with some defect—from one-fourth to one-third of them mentally retarded.) The results of other recent research virtually promise to eliminate a complication of Rh incompatibility that used to kill 5,000 infants a year and led to retardation in many of the survivors. The lifetime care of a seriously retarded child comes to well over \$100,000; lost income is probably well in excess of \$500,000. Every time a case of serious retardation is prevented, the country saves in the neighborhood of three-quarters of a million dollars.

In considering priorities in the field of prevention, the Task Force concluded that services for children, particularly those under the age of five years, should have first place. The years from birth to five, sometimes referred to as "the lost years" because so little attention has been paid to them, are the period during which the pattern of later life is laid down. And this is the period in which preventive intervention has its highest potential.

BIOLOGICAL AND ENVIRONMENTAL FACTORS

Since biological and environmental factors are often interrelated in the cause of mental disability, they must be considered together in its prevention.

In mental retardation, several of the more serious forms due to maternal infections, malnutrition during pregnancy, and birth injuries are preventable if adequate prenatal and obstetric care can be assured. Prematurity, which is known to be associated with retardation and other disabilities, has a link with low socioeconomic status, among other factors, and thus should be preventable in part. Some of the rare inborn errors of metabolism may be prevented through the genetic counseling of prospective parents, and in others the effects of the disorder can be lessened by special diets if the condition is recognized at birth or soon after.

As noted earlier, we can now prevent two conditions that may lead to brain damage—rubella in pregnant mothers and a complication of Rh incompatibility. Retardation in childhood caused by poisons such as lead and by infections such as measles is also within the scope of prevention.

However, when a condition that may lead to a biologically-based disorder occurs under circumstances of poverty and other social deprivations, its danger is likely to be unrecognized and the services necessary to prevent serious consequences are often outside the reach of those who need them.

It is now believed that the milder but far commoner forms of retardation spring directly from unfavorable environmental factors, which can inhibit emotional and intellectual development. Here, too, preventive measures can be effective.

In mental illness, except in rare forms, the role of biological factors has not yet been so clearly demonstrated as in the severe types of mental retardation. There is reason to believe, moreover, that even when a biological factor is present, the environment in many cases may determine whether or not it becomes operative. In any event, environmental circumstances, particularly within the family during early life, play an unquestioned role in the development of much mental illness. Also there is no doubt that environmental disadvantages can foster a host of unhealthy attitudes of mind that show themselves as disorders of behavior such as juvenile delinquency, drug addiction and the criminal activity that supports it, alcoholism, violence, and racism.

Often the unhealthy attitude of a young person has been traced to faulty parental behavior ranging from neglect to positive ill treatment and including the encouragement of antisocial activity. Clearly there is scope here for prevention through parental education and counseling.

The Task Force endorses the view that manifold environmental disadvantages, discussed at more length in the chapter on social problems, are not only incompatible with mental health but also an encouragement of mental disability. It recognizes that the correction of these social evils is an objective that should be pursued as part of the long-term campaign for improving the quality of life of the Nation irrespective of its implications for the prevention of mental disability. *The Task Force does, however, most strongly urge that due and early attention to the prevention of mental disability and to the needs of the mentally disabled be paid in any program either projected or already operating in the social field, particularly those programs directed towards improving conditions in the inner cities and impoverished rural areas.*

RECOMMENDATIONS OF JOINT COMMISSION ENDORSED

The Task Force had available for its deliberations a summary of the recently completed work of the Joint Commission on the Mental Health of Children. The Commission points to many inadequacies in the Nation's services for children. In particular, noting the rapidly increasing number of children in State mental hospitals, it underlines the urgent need for comprehensive children's services in the community. And it observes that unless programs for children can be given visibility at the highest level, the needs of children will be submerged—as they have been in the past—in the competing pressures for other services.

The Task Force looks forward to the establishment of an advocacy body, as recommended by the Commission, that will ensure awareness at all levels of society of the needs of children and will relate with the Joint Council on Disabilities that the Task Force has recommended. An advocacy system is intended to provide advisors and proponents of the needs of children at every level, from the President to the county or town executive. It aims to improve the linkage and coordination of services for children at Federal, State, and local levels. It would include an *ombudsman* function under which individual children and their parents or guardians would be helped to find the services required and to move without impediment from one service to another.

The Task Force endorses the following recommendation:

“The Commission recommends that Federal funding be provided for the establishment of an advocacy system at every level of society.”

The Joint Commission on the Mental Health of Children emphasized the importance of the first five years of life in the prevention of many

major social problems. Violence and crime have their developmental roots in problems of learning to manage angry and selfish feelings in the earliest years of life. If physical and mental disabilities evident in that period remain untreated, they lead to grave difficulties in school, to serious emotional problems, and even to mental illness.

The Task Force shares the Commission's views on the critical importance of these early years and endorses the following recommendation:

"The Commission recommends the creation of a network of comprehensive, systematic services, programs and policies which will guarantee to every American from conception through age 24, the opportunity to develop to his maximum potential."

FAMILY PLANNING

The Task Force is aware that the President is the first to have sent a message to the Congress on the problems of population growth and family planning. The present rapid expansion of the population threatens the quality of life for this and future generations. From 10 million in 1830, the number of people has increased to more than 200 million at present, and an additional 100 million are expected during the next 30 years. Unchecked, this continuing expansion threatens to exacerbate all the social problems—including poverty, overcrowding, unemployment, inadequate housing, malnutrition, violence—associated with higher rates of mental disability.

Voluntary population control is essential if the United States is to achieve a better balance between rates of birth and population density and avoid further overcrowding while the Nation works to solve its already grave social problems. To this end the country must expand birth control programs to the point where family planning information and birth control measures are freely available in every State and at every socioeconomic level. Additional research in reproduction and control of reproduction is required. Studies of the most effective ways of making existing information and means of control widely available are needed also.

The Task Force notes with approval that many Americans—as reflected in recent legislative and judicial decisions—are changing their attitudes toward the termination of unwanted pregnancies. In the interest of both maternal and child mental health, no woman should be forced to bear an unwanted child. For today's unwanted children, far more so than the others, are likely to be tomorrow's alienated, violent, mentally disabled, or criminal.

Avoidance of unwanted births would have a direct as well as an indirect effect on preventing mental disability. Estimates have been made, for example, that it would reduce prematurity—which is associated with mental retardation—by almost 20 percent, congenital malformations by more than 20 percent, and Down's syndrome by more than 30 percent.

Rec. 2.—The Task Force recommends that the government provide active leadership for increased support of birth control research, increased dissemination of birth control information, and increased availability of birth control measures and voluntary sterilizations and abortions.

PRENATAL AND PERINATAL SERVICES

As suggested earlier, good care during the period of pregnancy and childbirth can prevent certain conditions that may lead to mental disability and detect others early enough for effective treatment. But such care is not available to many women, particularly those of impoverished areas, unless they are reached by one of the Department of Health, Education, and Welfare's Maternity and Infant Care projects. Included in these projects are diagnostic, preventive, and treatment services, along with information about child care, to ensure good maternal and child health throughout pregnancy and the infant's first year of life.

With the development of techniques that make it possible to study the fetus and note defects—and perhaps, in the near future, to correct them—such maternity and infant care programs have assumed an even more vital role in the prevention of disability, whether mental or physical. They should be universally available.

Rec. 3.—The Task Force recommends that prenatal and perinatal services such as those offered in the Maternal and Infant Care projects be made available to all who need them. These should include the newer diagnostic, interventive, and preventive techniques.

DAY CARE—EARLY SCHOOL

Day care programs, provided they make full use of existing knowledge about the development and education of very young children, have an enormous potential for the prevention of unhealthy attitudes, the detection and treatment of early mental abnormalities, and the prevention of functional retardation. The Task Force gave much thought to the conditions under which early preschool education could achieve the best results. There was general agreement that early education should be

available to children of all socioeconomic levels. Further, an early school under the public system should offer as good a service as that available in the best of private schools for very young children.

Unless these conditions are observed, the Task Force believes, a variety of day care programs will grow up serving separate sections of the population related to social class and financial status. If this happens, the potential impact of early education in the prevention of racism and other negative social attitudes will be lost.

It is important that the children's families be involved in any system of early care and education, and essential that the system be able to call on the full range of health, mental health, educational, and social services that may be required. For the sake of each child's well-being, the information collected about him during these early years should be available to the regular school system when he enters it and be used in planning services to correct problems that may have appeared.

Rec. 4.—The Task Force recommends that a system of universally available day care programs, from infancy to school age, be established under a variety of auspices. These programs should involve the children's families, collaborate with health, mental health, educational, and social services, and provide continuity at school age with the services of the regular school.

EARLY SCREENING

There is considerable evidence that it is now possible to identify in the preschool years—and if not then, certainly in the first and second grades—children who are either socially maladjusted or academically inadequate. Special programs that provide some individual attention at this point, the evidence also indicates, will tend to prevent the development of either emotional maladjustment or academic retardation.

Rec. 5.—The Task Force recommends the expansion of programs to detect problems of social adjustment and intellectual competence in preschool and primary-grade children. Early individual management of these problems should be provided.

SCHOOL PROGRAMS FOR MENTAL HEALTH

The growth of the educational system to include almost all children from the ages of 5 or 6 up to the late teens, and the tendency to lower the starting age to 2 or 3, means that the schools have a greater opportunity than ever before to work for mental health. Indeed, where parents

are unprepared for their role and cannot be reached through home-visit or other programs of parent education, the schools are the primary system for preventive work.

The prevention of mental disability depends in part on the presence and quality of specific programs for the detection and treatment of emotional and intellectual difficulties. It depends also on the quality of the relationship between teacher and child and of the atmosphere of the classroom. And this is significantly affected by the quality of the administration and of the system of which the individual school is a part.

Preventive programs are being strengthened—and can be further strengthened—by the application of research findings along many lines. For example, we now have better information on how a child learns basic perceptual and intellectual skills; how, through better management techniques, the classroom experience can be made more rewarding for teacher and pupils alike; how, through appropriately planned therapy, many disturbed children can attend regular schools and benefit from their programs, thus facilitating recovery and preventing more serious illness. We now know that many children regarded as emotionally disturbed or mentally retarded have a remediable learning problem that needs to be treated promptly to prevent more serious disability.

Further, we know that many disadvantaged children need special educational services very early in life—whether delivered through home visits by specially trained teachers or aides or in day care centers—if their intellects are to develop fully.

In the area of school programs for better mental health, a major problem is to apply what we already know.

EDUCATION FOR FAMILY LIFE

There is strong evidence that faulty emotional and intellectual development during early childhood contributes to and may even cause mental illness both in later childhood and in adult life. And retardation of the functional type may arise when parents or parental substitutes fail to supply the stimulation and the teaching necessary for the young child's intellectual development. Thus, both mental illness and retardation may be passed from generation to generation through cultural inheritance: the child whose early home life left him with a mental disability becomes the parent who, unknowingly, provides the same kind of home life.

In the light of present knowledge, a basic measure to prevent mental disability is to reach parents and prospective parents with information about good health practices and the family-life attitudes and experiences conducive to sound emotional and intellectual development.

Rec. 6.—The Task Force recommends two simultaneous approaches to better informed parenthood:

- (a) **PARENTAL EDUCATION.**—An effort to provide family-life and health information to young parents through such means as well-baby clinics, public and private social agencies, public school, adult education courses, and the educational campaigns of community mental health centers;
- (b) **EDUCATION FOR PARENTHOOD.**—A curriculum on parenthood, and family life, including health measures, to begin in the elementary grades and continue through high school at least.

HELP FOR CRISIS PERIODS

The course of every life, no matter how ordinary, is marked by crises potentially hazardous to mental health. Leaving home for the first time—for work, school, military service—is a crisis. So are getting married, changing jobs, becoming a parent, losing a loved one, having an operation, going through change of life, seeing the last child leave home, retiring. The way an individual handles a crisis may strengthen his mental health and leave him better able to cope with the next crisis. Or it may increase his vulnerability to, and even bring on either physical or mental illness.

If counseling services for people troubled by such a crisis were available and used, they would prevent many cases of mental illness and catch others before they became serious. These services should be available in every community mental health and mental retardation center. And clergymen, general practitioners, nurses, lawyers, and others to whom people often turn first should be aware of these services and even prepared—perhaps as the result of the center's consultative or training programs for community caretakers—to offer appropriate guidance in some cases themselves.

CHAPTER V

Treatment and Short-Term Care

MENTAL RETARDATION

Because mental retardation, whatever may be the cause, is an abnormality of development, it usually shows itself in infancy or early childhood. The earlier in life it is detected the better will be the chances of correcting or modifying the disabilities with which it is associated.

The Task Force was therefore concerned that all those involved in the health, education, and welfare of infants and children should be aware of the importance of the early recognition of mental retardation, of the forms in which it shows itself, and of where to go for information, care, and treatment.

The Task Force draws particular attention to the need for early diagnosis, evaluation, and treatment of the physical disabilities, including defects of speech, sight, and hearing, that are so commonly associated with mental retardation and emotional maladjustment and that are amenable to correction.

With the emphasis changing from institutional to community care, some of the mentally retarded will require continuous support in the community throughout their lives. The resources to meet their needs will vary with age: diagnosis in infancy and childhood, followed by special schooling and vocational training, sheltered employment and recreation in adult life, and guardianship when family support is no longer available. A flexible and comprehensive program must be developed to cover these diverse needs for the full life span.

In the field of mental retardation, as in mental and physical illness, there is an urgent need to develop resources and improve delivery of services. It is essential that resources (facilities, agencies, personnel) be planfully created, upgraded, and allocated so that as funds become available to pay the costs of social, rehabilitation, and health services to the handicapped and disadvantaged, quality services are at hand. Legislation should permit and encourage States to use and develop voluntary agency resources, and also to improve and reorient public services and facilities in accordance with modern standards.

Rec. 7.—The Task Force recommends expansion of programs and facilities for the diagnosis, treatment, and rehabilitation of the mentally retarded. The need for expanded community services and improved

institutional programs leads the Task Force to recommend legislation that will assist the states and communities to carry forward the state comprehensive mental retardation plans initially developed during the late sixties.

MENTAL ILLNESS

The main guidelines for the early and effective treatment of mental illness are laid down in the Community Mental Health Centers Act. The Task Force noted that the predicted decrease in the total number of patients in State and county mental hospitals is continuing but that an increasing number of children and young people are being admitted to these institutions. The Task Force emphasizes the importance of treating children whenever possible within the family setting and feels strongly that comprehensive treatment programs for children should be provided as part of community mental health centers.

The Task Force recognizes the critical importance of preventive and early intervention services for children as a key means of preventing the development of problems such as narcotic addiction, delinquency, and severe mental illness.

A particular area of concern where difficulties are developing far more rapidly than either concepts or resources to deal with them is the adolescent age group. Adolescents are being admitted increasingly to our public and private mental hospitals because of problems that range from drug abuse to frank psychoses. If the special needs of adolescents in the grip of serious mental, emotional, and social difficulties are to be met, psychological, educational, and vocational resources must all be tapped.

Rec. 8.—The Task Force recommends the continued expansion of comprehensive community-based programs, with new emphasis to be given to developing within these programs special efforts to deal with the mental health problems of children and youth, including the abuse of drugs and alcohol.

In addition to the best available treatment for the child or adult with a mental disability, families may well need other services if the desired person is to live at home. Money, transportation to the treatment center or school, emotional support, help with the children, a day off—any or all of these may be essential to keeping a stressful situation within bounds. Though treatment centers for people with mental disabilities may be concerned with the needs of the family as well as those of the patient, they may not always have the manpower to do much about their concern. This is an area in which volunteers might be of particular use.

SERVICES FOR THE ELDERLY

Nowhere in the field of health is the sharp distinction between mental and physical factors less warranted than in geriatrics. Of the 19 million Americans over 65, more than a fourth have a psychiatric disorder warranting intervention. People over 65 make up almost 30 percent of the residents of public mental hospitals and they constitute almost 20 percent of all first admissions. However, much of the mental impairment in the over-65 population springs from the individual's responses to the normal physical changes of aging and, perhaps more, to the reduction of opportunities for human contact. Boredom is frequently a contributory factor.

The large and growing number of people exposed to the disabilities of age gives society a formidable challenge to supply preventive measures, treatment, and other services.

Widespread health education, with attention to the physiological and psychological problems associated with age, is of course an essential—indeed the basic—element of prevention. It can help minimize both the number and the severity of the problems. And it can make those people who are close to the elderly more understanding of their behavior and more sensitive to their needs—for self-esteem, for regard in the eyes of others, for concern with what they have to give and not alone with what they must be given, for help in keeping in touch with the world. This last is an area in which volunteers, particularly the young and the middle-aged, can do much to help.

Illness in the elderly often presents a picture of mixed medical, social, and psychiatric problems, and the medical problems often involve several different specialist departments. The physical as well as the psychiatric components of disease in the elderly, if diagnosed early, respond reasonably well to short-term treatment. However, the immediate danger to life lies more in the physical. This fact, coupled with the need for medical expertise and complicated diagnostic equipment, suggests that a geriatric program is better associated with a general medical rather than with a mental health organization. But a psychiatrist should be readily available for consultation and treatment, along with a social worker who would be concerned with what happens to the patient following recovery or rehabilitation. A geriatric program should also have some nurses experienced in the care of the mentally ill.

Psychiatric and health consultation are also required for the growing number of old people in nursing, boarding, and old age homes. Provision for adequate recreation programs and other activities in which volunteers can be immensely helpful will materially enhance the quality of patient care.

For people who do not respond satisfactorily to treatment for a mental

disability, the community mental health centers should serve as backup facilities and provide specialized psychiatric care for at least a limited period. Every reasonable means should be taken to keep people in the community rather than sending them to State mental hospitals.

Rec. 9.—The Task Force recommends the establishment of community-based geriatric programs, each serving a defined geographical area and providing diagnosis, short-term treatment, and placement. Though separately funded and staffed, these should, wherever possible and appropriate, be affiliated with a comprehensive health center and include psychiatric consultation services. In other facilities and programs now caring for the aged, adequate health care and psychiatric consultation services must be available.

DRUG ABUSE AND ALCOHOLISM

The Task Force associates itself with the view that narcotic drug addiction, as well as alcoholism, is an illness and the narcotic addict a sick person in need of treatment and rehabilitation. Abusers of non-narcotic dangerous drugs also need treatment. The Task Force therefore considers that decisions relating to dangerous drugs should be made only on the advice of scientific agencies, and it commends the Administration for viewing drug abuse as a problem of public health and not simply of law enforcement.

The most valuable measure for both controlling and preventing drug abuse, the Task Force is convinced, is better public information. This demands more nearly adequate knowledge, which can spring only from research; it also demands expanded efforts to reach people—particularly young people—with the facts already known about dangerous drugs.

Narcotic drug addiction. The number of active narcotic addicts may be from 50 to 100 percent higher than the 65,000 reported by law enforcement agencies, and it appears to be growing, particularly among young people. With increased support, the anti-narcotic campaign has led to many advances—for instance, better understanding of the social and psychological forces impelling some individuals to use heroin and other hard drugs, more detailed information about the physiological and psychological effects of these drugs, new drugs and techniques for treating addiction, improved means of detecting drug use, and a number of new community centers for treating addicts. Nevertheless, more information about the factors involved in addiction—and these are numerous—and about effective treatment is badly needed, as are additional treatment facilities, whether in special clinics or in community mental health centers, and training programs for staff to man them.

Marihuana. With some 200–250 million people using it, this drug is the world's most popular intoxicant except alcohol. Its use in the United States has spread with the rapidity of an epidemic. Perhaps 12 million Americans have had at least some experience with it; surveys suggest that half of the student in some urban and suburban high schools have tried it. Not enough is known about either the short-term or long-term effects of marihuana. Only fairly recently, in fact, has its active principle been synthesized, greatly facilitating research. It is clear that more research into the effects of marihuana is urgently called for.

Other non-narcotic dangerous drugs. Between a quarter and a half million people—including those addicted or habituated to such agents as the barbiturates, the amphetamines, and certain tranquilizers—are estimated to be non-narcotic drug abusers. The number probably is on the rise. The annual production of the barbiturates and the amphetamines is sufficient to provide 40 doses for each man, woman, and child. Fewer people seem to be using LSD, but it does still attract experimentation by teenagers. For persons who abuse such drugs, treatment and rehabilitation should be available through the regular mental health services.

Alcoholism. The abuse of alcohol exacts an enormous toll of the health, wealth, and happiness of the Nation. Close to 11 million Americans are alcoholics, only a small proportion of them the skid-row type. About 200,000 drinkers become alcoholics each year. Though continuing research into causes and better methods of treatment is essential, much knowledge is already available. With appropriate resources, including appropriate attitudes and motivation on the part of the treatment staff, alcoholism is as treatable as any psychiatric disorder. A success rate better than 50 percent—though only 25 percent with skid-rowers—has been reported by some outpatient departments. The problem is that resources for using the existing knowledge are quite inadequate. Particularly strong is the need for treatment facilities in the community for those alcoholics chronically arrested for drunkenness, who have been traditionally handled in most jurisdictions through the “revolving door” of the correctional system.

Rec. 10.—The Task Force recommends a substantial increase in Federal resources to support research, training, community-based treatment facilities, and public education to combat two major problems affecting our national health—drug abuse and alcoholism.

The effect of alcoholism on workers in industry is of special concern to management and organized labor. Hence, the Task Force suggests that these two groups—with governmental support, possibly including seed money—join in planning programs for the delivery of services to workers suffering from alcoholism, and to members of their families. The services might be provided through a variety of means including

community mental health centers, hospital clinics, factory health clinics, and private practitioners. Such services might point the way to a joint approach—discussed below—to the general problems of mental disability in industry.

FEDERAL LEADERSHIP FOR MENTAL HEALTH IN INDUSTRY

In considering ways of enlisting the private sector in the development of services for the mentally disabled, the Task Force recognized that workers in industry and their families constitute a substantial proportion of the population. It recognized also that many of the problems of the mentally disabled are more easily resolved when treated within the framework of the job.

Along with government, both employers and employees have a clear interest in preventing, and in reducing by effective treatment, the wastage due to mental ill health. Those directly affected include management personnel as well as production and service workers. Although the employees of a few industrial organizations and members of certain unions are covered by special plans, the majority—and their families—remain without adequate resources for dealing with mental disability.

Cooperation among employers, employees, and government for mental health could make a significant contribution to the quality of life of a large proportion of Americans. In such cooperation, the Task Force sees a unique opportunity.

Precedent for such joint endeavors has been set by the manpower training programs, in which trade unions and management collaborate under government financing. This pattern could be followed in joint planning for the delivery of mental health services to workers in industry and their families.

Rec. 11.—The Task Force recommends that steps be taken to encourage employers, organized labor, and government to collaborate in the planning and provision of treatment, rehabilitation, and prevention services for workers with mental disabilities and their families.

SPECIAL EDUCATIONAL NEEDS

By conservative estimates, more than 3 million mentally ill or mentally retarded children are enrolled in public schools. All of these need special educational services of one kind or another if they are to overcome their disabilities or learn to live effectively in spite of them. Yet

less than one-half—in some States only one-tenth—are receiving any kind of special service. For many who do receive some services, the special programs end with elementary school, whether or not the children are then able to progress satisfactorily without them. Moreover, most of the children in mental hospitals or in institutions for the retarded are receiving quite inadequate, if any, education.

The Task Force subscribes to the principle of equal educational opportunity for all, including children with mental disabilities. Whether these children are in the community or in institutions, they have a right to the best possible education. To the majority of them, this right is now denied.

In very many cases, it is now within our capabilities to remove children from the category of the mentally disabled—to “cure” them—if the necessary resources can be applied at the right time and place. And most of the others can be helped to a higher quality of life.

As noted in the section on prevention, often the right time to intervene is early in the developmental process. There is some evidence from research projects that the level of intellectual functioning can be raised substantially through preschool programs. These projects were for children with a high risk of being labeled as slow learners or as mentally retarded. Other projects have found that even seriously disturbed children, many of them, can benefit from preschool classes. With adequate preschool education or day care programs universally available, it seems clear that a substantial proportion of mental disability would be either prevented or detected early enough for successful and relatively rapid treatment.

To ensure equal educational opportunity for children with mental disabilities, the following needs must be met:

1. Expansion of existing educational services to all children with mental disabilities who are now enrolled in the public schools or who could be enrolled if there were services.
2. Extension of special educational services to disturbed or retarded children of preschool age and to those young people and adults who continue to require them beyond the usual period of public school.
3. Improvement of educational services in those institutions for disturbed or retarded children which now have them and the inauguration of such services in the institutions which do not.
4. Additional research into strategies for educating children with disabilities.

To meet such a program, the Nation will have to produce many more special education personnel. And, since no training program likely in

the near future will produce enough such people—a three-fold increase in the present number—the Nation will also have to make more effective use of regular classroom teachers, of subprofessionals, and of volunteers. Experience shows that with some training in the principles and techniques of working with disturbed and retarded children, many regular teachers and even nonprofessionals perform very well.

Rec. 12.—The Task Force recommends that special educational services, now reaching less than one-half of the children who need them, be made available, in the public schools and residential institutions, for all disturbed and retarded children.

CHAPTER VI

Rehabilitation and Extended Care for the Mentally Ill and the Mentally Retarded

By rehabilitation is meant the process of compensating for, or adapting to, the effects of mental or physical disability. In the case of the mentally disabled the aim of rehabilitation is to increase social competence by retraining to mobilize assets and, by manipulating the environment, to minimize defects and enable the individual to circumvent them. More than 35 percent of the people who have been rehabilitated under the State-Federal program of vocational rehabilitation have been those with mental disabilities.

IMPROVEMENT OF INSTITUTIONAL CARE

The rehabilitation of the resident population of institutions for the mentally ill and the mentally retarded is linked with the urgent need for the general improvement of these institutions. In this connection the Task Force shares the views of the President's Committee on Mental Retardation which, in 1968, referred to the conditions in State institutions for the retarded as "a national disgrace." *It supports the Committee's recommendations: First, that the Hospital Inservice Training Program, Hospital Improvement Program, and Foster Grandparent Program be extended; second, that standards and accreditation in the areas of residential care, rehabilitation, and education be widely promulgated and enforced; and third, that institutional care under the State be supplemented by a variety of systems under different auspices and that the needs of the retarded be recognized in community planning and in any future welfare reforms.*

The Task Force warmly endorses the move, becoming increasingly strong, to replace existing institutions for the mentally disabled by much

smaller, homelike units located within the community and incorporating new architectural concepts. The demand for resources to build these new facilities may seem to conflict with the demand for resources to upgrade the old one, but the Task Force feels that the two objectives are equally necessary. The new facilities are needed for a more effective fight on mental disability. The old ones must be improved for treating more effectively those people who must use them during the transition period and for serving more humanely those who will require institutional care the whole of their lives. The Task Force is glad to note that mental retardation hospital improvement projects increasingly are being coordinated with vocational rehabilitation services.

Rec. 13.—The Task Force recommends the immediate improvement of institutional services and the setting of minimum quality standards. Specifically, it recommends that the Hospital Improvement Program and the Hospital Inservice Training Program for the mentally ill and the mentally retarded be given increased resources.

REHABILITATION SERVICES

Rehabilitation in the community is required both for persons who have never been in an institution and, as a step towards resettlement, for those who have graduated from institutional care. Whether they are mentally ill or mentally retarded, the essential process consists of a retraining in old skills or an introduction to fresh ones better fitted to their capabilities or in greater demand.

Essential adjuncts to a system of rehabilitation in the community are foster homes or hostels in which people can live during the period of retraining and until they become able to live independent lives. There will be some who, though unable to attain complete independence, require and are capable of regular work under protected conditions. Sheltered workshops should be available for these.

As evidence of the heartening payoff to be expected from rehabilitation efforts, it is estimated that nearly 80,000 mentally ill and about 39,000 mentally retarded people will be placed in gainful employment during the current fiscal year by the State-Federal program of vocational rehabilitation. Working cooperatively with voluntary groups as well as with concerned public agencies, the State rehabilitation agencies have made extensive use of grant resources available through the Federal partner in the program, the Rehabilitation Services Administration, in expanding rehabilitation services for those with mental disabilities. Leadership and financial support have been provided, for example, in (1) the establishment of rehabilitation units at State mental hospitals and halfway houses,

to facilitate the transition of former mental patients from institution to community, and (2) the initiation of collaborative special education-vocational rehabilitation activities designed to enable the retarded person who is in school to transfer at the proper time from the world of school to the world of work.

Initially established to place physically handicapped people in remunerative employment, the State-Federal program increasingly has been involved in serving people having other types of disabilities and in meeting needs other than strictly vocational. For example, the program now has authority to provide services not only to the handicapped person but to members of his family as well and to provide evaluative and pre-vocational services to people who are disadvantaged but do not have an actual physical or mental disability.

Rec. 14.—The Task Force, commending the State-Federal program of vocational rehabilitation for its successful efforts to help disabled people lead independent lives, recommends increased support of the program at both Federal and State levels.

The Task Force considers that it is in this wide area of vocational training and rehabilitation that the effort of volunteer workers could make its greatest impact. It points out in this connection that unless jobs are available at the end of the rehabilitation process, the work that has gone into it will have been wasted in large part. And it expresses its gratitude to the President's Committee on the Employment of the Handicapped for its efforts to see that jobs *are* available.

Rec. 15.—The Task Force commends the work of the President's Committee on the Employment of the Handicapped and recommends that an even greater national effort be made to publicize the needs of the mentally disabled for employment and their value as employees.

CHAPTER VII

Social Problems and Their Relationship to Mental Disability

The reciprocal relationship between mental disability and social problems such as racism, poverty, violence, crime and delinquency, and overcrowding is real and complex. Racism is declared by many authorities to be the Nation's number one mental health problem. Substandard housing and education, which are correlates of racism and poverty, are associated with higher rates of mental retardation and mental illness. Violence, ranging from civil disorders to street crimes, from wars to assassinations, causes mental anguish. Mental instability, in certain cases, causes violence. Environmental pollution has its effects on both body and mind. Individuals impaired—physically, mentally, or emotionally—by environmental and social outrages cannot function efficiently as citizens to correct them.

It is inappropriate to rest the case for improving social conditions solely on the rationale of preventing mental retardation and mental illness. Yet improvement of these conditions will help substantially to prevent mental disability. Conversely, programs directed towards preventing mental retardation and mental illness will improve social conditions.

POVERTY

The mechanisms by which poverty contributes to mental disability are subtle at times, as in the effect of malnutrition on brain and intellectual development, and clear at other times, as when poor housing and inadequate child rearing lead to ingestion of lead paint chips, causing bone and brain damage. Other sequelae of poverty are less obviously biological in their operations but as profound in their impact. There is evidence that the majority of persons with minor forms of mental retardation come from poverty areas. Further, children raised in an atmosphere of hopelessness and apathy, or in chronic anxiety and surrounding hostility, do not easily develop into mature, stable citizens. And children whose lives, through poverty, are dominated by the need for day-to-day survival are unlikely to acquire a concern for others and a respect for law and order.

The Task Force considers that poverty—independent of color, race, or creed—is the most important single factor in the production of the social ills to which it refers in this report. It commends the President for his development of a social program that starts us on the road to assuring an adequate minimum income to all our people.

VIOLENCE

National concern over tragic individual and collective acts of violence led to the Kerner and Eisenhower Commissions. Their reports stress underlying causes of violence, including alienation, lack of nonviolent options for certain oppressed groups, increasing polarization of racial attitudes and, therefore, increasing fear, and growing distrust of some governmental institutions.

The Task Force urges continued Presidential leadership in a national campaign to understand and reduce domestic violence through biological and social research; violence prevention centers, *ombudsmen* and other such innovative aids to protect the dignity and prevent further alienation of oppressed groups; effective gun controls, and general attention to reducing the rhetoric of violence and the portrayal of violence as a method of problem-solving in America.

RACISM

Although opportunities for adequate housing, education, and jobs have improved for minority people in the last decade, true equal opportunity remains a goal to be reached.

The obviously degrading, humiliating discrepancy in opportunity is a serious frustration to the dignity and mental health of all our citizens. The effect on children of minority groups is even more profound and tragic. *The Task Force commends the report on the Mental Health of Minority Children in the Joint Commission report on Mental Health of Children. In essence, the Task Force and the report agree that the shortsighted, irrational, prejudicial attitudes of many Americans, attitudes which too often have been nurtured by the family, church, and school, seriously interfere with our maturing into a nation of humane, healthy individuals.*

ANTISOCIAL BEHAVIOR

Delinquent and criminal behavior is usually viewed as the end result of interactions among a host of factors—biological, psychological, social, cultural. While the exact nature of these interactions is poorly understood, there is general agreement that behaviors violating sociolegal norms are often symptomatic—as mental illness often is—of social as well as individual distress and dysfunction. These are deviant behaviors. Whether or not they are also labeled delinquent or criminal behaviors can depend in some cases on what jurisdiction or agency is doing the labeling. In any event, they have rightly been the concern of our mental health system. With knowledge of the roots of problem behavior increasing, and with the police and the courts looking more and more frequently to mental health agencies for assistance, this concern is on the rise.

The Nation's mental health system should have the means to inquire much more fully into the causes of antisocial behavior, the most effective ways of preventing it, and the most fruitful policies and techniques for rehabilitating those who have engaged in it. And the juvenile and criminal justice systems should apply much more extensively what is already known about these problems, particularly the rehabilitation of young delinquents and pre-delinquents. The mental health system and the juvenile and criminal justice systems should continue and further improve efforts to work much more closely together on problems of mutual concern.

Recent research suggests that, for those able to use such services, increasing emphasis should be placed on intensive, community-based treatment programs. These can rehabilitate more people at less cost. Equally important, such programs prevent exposure to the atmosphere of penal institutions, which too often fosters emotional disorders and criminality.

Research points also to ways of making programs in prisons and reformatories more effective. A pilot project of self-instruction and vocational training in one State correctional center, for example, led not only to a substantial increase in earnings when the offenders were released but also to a substantial decrease in the recidivism rate. Efforts to tailor the treatment to the type of individual seem another promising approach.

Rec. 16.—The Task Force acknowledges the needs of the criminal justice system in coping with the problem of crime; at the same time, it recommends that the Administration give increased emphasis to crime and delinquency as a mental health problem.

THE MENTALLY DISABLED OFFENDER

A review of the current efforts of the Administration and government agencies to improve the courts and the correctional system indicates a need that should be highlighted—special attention to the problem of the mentally ill or mentally retarded offender. There are many such offenders. In State prisons, for example, the proportion of individuals with low I.Q.'s—in the retarded range—has been estimated at more than three times that in the general population. And when inability to function socially is added to intellectual disability, one-third of our prison population can be considered retarded. Nevertheless, the mentally disabled person typically receives little or none of the special care needed if he is to be rehabilitated. Studies have shown, too, that the psychiatric and intellectual characteristics of individuals brought before the courts are inadequately considered from either the medical or legal point of view.

As the report of the President's Commission on Law Enforcement and Administration of Justice pointed out, innovative approaches to avoid incarcerating mentally disabled persons are essential. One such approach can be made very early in the criminal justice process—the diversion of mentally ill and retarded defendants to other social systems, notably mental health and rehabilitation, better able to meet the needs not only of the individual offender but also of society.

Rec. 17.—The Task Force recommends that high priority be given to means of ensuring special attention for mentally ill and mentally retarded offenders at all points in their dealings with the mental health and criminal justice systems. This would be an appropriate subject for consideration by the Joint Council on Disabilities.

THE LAWS RELATING TO THE MENTALLY DISABLED

The care and treatment of the mentally ill and the mentally retarded are often closely related to the laws governing commitments generally and those dealing with the guardianship of the mentally retarded. Since the publication in 1961 of the monumental work by the American Bar Foundation, "The Mentally Disabled and the Law," a number of important legislative changes have been made and a number of major problems have arisen. Prominent among the issues needing consideration are the desirability of diverting mentally ill or retarded law violators for handling by the mental health, rehabilitation, and other community systems; increased use of outpatient and community-based treatment facilities as opposed to commitment to State institutions; and concerns

about the "right to treatment," "adequacy of treatment," and the overall civil rights of the mentally ill and mentally retarded as recently discussed in several appellate decisions.

In short, new concepts and new programs make new laws imperative. It is inappropriate to commit a person to an institution if the more effective care-giving entity is a system of services in the community. And it is unjust routinely to deprive a person of certain rights—to vote, for example, and to drive a car—solely because he has been treated for a mental disability.

Careful study might also be made of some recently revised laws governing the commitment of mentally ill persons, such as the Lanterman-Petris-Short Act signed into law in California in 1968, which seeks to ensure that persons committed for care and treatment do not become lost on the back wards of State institutions. Its companion, the Lanterman Mental Retardation Services Act of 1969, which deals with the provision of a continuum of services to suit the individual needs of the mentally retarded, is also worthy of study.

Rec. 18.—The Task Force recommends that the laws concerning the mentally ill and the mentally retarded be reviewed and that model mental health and mental retardation acts be prepared for consideration by the State legislatures. The Joint Council on Disabilities would be particularly qualified to sponsor this activity.

CHAPTER VIII

Financing Mechanisms, Organization and Delivery of Programs and Services

Programs and services in the health, education, welfare, and human services scene in general have so increased in size and complexity that a whole new area of concern—the organization and delivery of services—claims attention. This takes in all levels—Federal, State, and community.

The organization and delivery of any set of services, such as those pertaining to mental health and mental retardation, must be seen in the context of the organization of all of society—in particular, how we govern ourselves. Society determines the services it wants and the mechanisms of paying the bills.

Of special significance to this Task Force was the changing organization of government itself. The Task Force became aware of and involved in understanding the President's commitment to a "new federalism." It studied documents and heard from the Director of the Office of Intergovernmental Relations so that it could better understand such issues as decentralization, revenue sharing, and block grants.

The general subject of financing of services is difficult to separate from the subject of organization and delivery. In fact, there is a clear, critical, and vital relationship between financing mechanisms and program shape and development. The relationship of the proposed revenue sharing, block grants, and other manifestations of the "new federalism" to program developments in the field of the mentally ill and mentally retarded was carefully explored. The Task Force is concerned that these new financing mechanisms carry out their promise to ensure better government and hence, ultimately, better services to people in need. The basic anxiety is that with development of nonspecific financing mechanisms, the least privileged, the most unfortunate, and those in greatest need will be neglected; hence, the recommendations on these matters.

MAJOR DEVELOPMENTS—DECENTRALIZATION, BLOCK GRANTS, AND REVENUE SHARING

The relationship between the need for improvement of government machinery and for shifting authority and responsibility back to States and localities, on the one hand, and the need for special attention to special needs, on the other, comes into sharp focus when a specific mechanism such as the block grant is considered.

The Task Force is aware of the reasoning behind that mechanism—that it will make for consolidation, simplification, and decentralization of the grant-in-aid process. However, adequate funds and support for the mentally disabled—the retarded and the mentally ill, the alcoholics and the drug addicts—have been hard won by a frank, special interest, special constituency approach.

The allocation of funds for the handicapped under Title I and Title III of the Elementary and Secondary Education Act is a case in point. Although the handicapped are estimated to include approximately 10–15 percent of the school-age population, only 2.4 and 3.5 percent of the funds under these Titles were allocated to the handicapped until 15 percent of the funds were explicitly earmarked for this purpose.

The Task Force is opposed to the complete removal of the categorical group of the mentally disabled because it is clear from experience that when this occurs, support for this group will diminish.

Rec. 19.—The Task Force recommends that, as block grants develop, special provision be made for a distinct allocation for the programs that involve the mentally disabled.

Another major component of the President's "new federalism" is the proposal for revenue sharing, which is due to start modestly in 1971 and build up over the following years. The Task Force is deeply concerned from its knowledge of past history that with the advent of "no strings attached" revenue sharing, the resources for the mentally disabled will not be maintained and may even decline precipitately. The proposed Joint Council on Disabilities will help ensure both national commitment and visibility for the mentally disabled. But still other social mechanisms may have to be developed to ensure adequate resources for this group as the country moves toward revenue sharing and tax rebates to States.

INADEQUACIES IN OUR PRESENT SYSTEM

In describing the present situation in health care, the President has used the word "crisis." So have other observers and leaders in fields of interest to the Task Force. This crisis is complex. One important dimen-

sion is the inequality between the demand on service systems and the capacities of these systems to meet the demand. Another dimension is the lack of coordination among the Federal, State, and local levels of government and also between the public and private sectors.

A general review of the systems related to the field of mental disability shows that a "system" may be a "non-system" or that even as a system may have become harmful to those who use its product—for example, a system that forces institutional commitment when community services would be preferable. Services are poorly distributed, uneven in quality, and not well coordinated. The Task Force feels that the suggestions and recommendations that follow will help to rectify this situation.

COORDINATION ISSUES AND INTERGOVERNMENTAL RELATIONS

The Task Force is aware that the relations between Federal and State agencies working in the area of mental disability are not always harmonious. In part this is due to the wide range and complexity of the problems with which they are dealing. But it results in part also from organizational complexities and lack of effective coordinating machinery. Close, harmonious relationships between Federal and State agencies are so important as to merit special study of means of attaining them. The relationship of the Federal and State governments to local government is also in need of attention.

Rec. 20.—The Task Force recommends that a special study of the administrative relationships among Federal, State, and local governments in the field of mental disability be undertaken and that recommendations for their improvement be made. This would be an appropriate undertaking for the Joint Council on Disabilities.

COORDINATION ISSUES AT THE FEDERAL LEVEL

The Field of mental disability is so broad that it touches many departments of the Federal Government, including the Department of Defense, Department of Labor, Department of Health, Education, and Welfare, Department of Justice, Veterans Administration, Office of Economic Opportunity, Department of Transportation, and others. The recommended Joint Council on Disabilities will be able to make a major contribution to coordinating and orchestrating the many programs involved.

The Task Force has studied the current mental health operations of the Federal Government in considerable depth. The role of the National Institute of Mental Health has been particularly impressive in filling several critical needs, including a coordinating function as well as a leadership role. Its dramatic success can be measured by the marked reduction in adult patient population of the State hospitals and the development of community alternatives through the community mental health centers. Basic to this success has been the bringing together of the three aspects of mental health—research, training, and services—under one organization with a designated leader. This administrative structure has permitted the careful and economic planning of manpower needs in relationship to services development. It has permitted the rapid use of research findings—for example, in psychopharmacology. The mental health field as a comprehensive entity has been able to develop social and behavioral approaches while still preserving its strong relationship to the health field.

Rec. 21.—The Task Force recommends that the National Institute of Mental Health continue as a unified comprehensive operation containing research, training, and services, and that it not be fragmented or altered but rather strengthened in its ability to relate and coordinate its efforts with health and social problems.

The need for coordination is especially pressing in the field of mental retardation. Several mechanisms to help achieve better coordination of mental retardation programs exist—among them the President's Committee on Mental Retardation and the Secretary's Committee on Mental Retardation. But no current mechanism is fully meeting the needs of the situation.

Study of this subject—the organization of mental retardation services in the Federal Government, particularly in the Department of Health, Education, and Welfare—brought out two major approaches to strengthening and improving the services. One is to move towards consolidating at least some of the elements of separate programs so that a "critical mass" of mental retardation programs is created. The head of this enlarged program would be better able to serve as an advocate leader of the mental retardation programs in the Federal bureaucracy. Several possibilities for consolidating elements were reviewed, and one drew particular interest—the inclusion in the National Institute of Child Health and Human Development of support for the University Affiliated Facilities program.

The second approach takes cognizance of the range of concerns embraced in the field of mental retardation and recognizes the need for a program and advocacy leadership role in each of the areas of health, education, welfare, and rehabilitation—and in research, training, and services. This approach considers the dispersal of programs throughout

the bureaucracy as both appropriate and in many ways the strength of the overall Federal mental retardation effort. However, in each of the major areas where mental retardation programs are presently located, there is a clear need to provide a sharper focus and improved visibility.

Rec. 22.—The Task Force recommends that the Secretary of Health, Education, and Welfare review the organization of mental retardation services within the Department of Health, Education, and Welfare and establish some mechanism for more effective coordination and greater visibility.

Rec. 23.—The Task Force recommends that the Joint Council on Disabilities in conjunction with the appropriate Secretaries review the organization of mental disability services at the interdepartmental level and recommend needed improvements.

COORDINATION AND ORGANIZATION AND MANAGEMENT ISSUES AT THE STATE LEVEL

The increasing importance of community programs for the mentally disabled and the impact of Federal efforts have made the State role more difficult and in many ways more important. The Task Force noted that the administrative burdens in such areas as State planning, review of local programs, and cooperation between public and private agencies have greatly taxed the leadership and personnel of State agencies.

The Task Force is in sympathy with the desire to strengthen State administration of programs in the mental health and mental retardation field. However, it is keenly aware that there are not enough trained, experienced individuals to carry out important responsibilities under State administration.

It is the conviction of the Task Force members that adequate funds devoted to such endeavors as staff development and inservice training of State program officials would pay handsome dividends in the more effective and efficient use of available public money.

Rec. 24.—The Task Force recommends that the Federal Government initiate an immediate program to train State and local government officials in the planning and administration of programs for the mentally disabled.

COORDINATION AND ORGANIZATION AT THE LOCAL LEVEL

The local level is where services finally reach individuals, families, and groups. Problems abound, and the Task Force notes only a few of

special concern: integration of local mental health and mental retardation programs with school programs in special education; coordination of mental retardation services; clarification and improvement of the relationship between community mental health programs and community mental retardation programs; and development of a mutually beneficial relationship between existing mental health and mental retardation services and growing day care programs.

Perhaps the most important, most fundamental concern should be for the citizen as consumer. The complexities with which a consumer must deal in obtaining services has led to the concept of *ombudsman*—a person who guides an individual through the maze of agencies and acts as his advocate to help bring about services where they do not exist. The application of this concept is one promising new way to help meet the needs of the consumer of services for mental disability. Further, the citizen consumer should participate in the actual design or modification of systems delivering human services. He can help those who provide the services to be more sensitive to the recipients' values and needs. And he can become an advocate in the battle for adequate resources. Another promising example is the multiservice center, which attempts to meet in a one-stop setting the full range of needs of poor urban individuals and families. The Task Force hopes that the development, application, and evaluation of these and other new mechanisms directed toward facilitating the delivery of services will be encouraged.

MEDICARE AND MEDICAID

These are prime examples of the importance of understanding and dealing with the interaction between financing sources and mechanisms on the one hand and program development and delivery of services on the other. Both Medicare and Medicaid contain limitations on benefits for the mentally ill and mentally retarded. These discriminations include limiting payments for care in general hospitals, limiting or excluding payments for care in psychiatric facilities and community mental health and mental retardation centers, and setting limits on the total number of days of care. The Task Force calls for changes in the Medicare and Medicaid laws in order to meet more nearly adequately the needs of people with mental disabilities.

In Medicare, important hospital benefits should be the same for mental as for physical disability. Out-of-hospital services—in particular, those of community mental health and mental retardation centers—should receive more consideration: they are effective and they are increasingly available. Coverage, now too strictly limited, should be

extended to such mental health professionals as social workers, occupational therapists, and speech pathologists when they work in organized settings such as a community mental health or mental retardation center.

But it is fundamentally more important—than these needed extensions of coverage—to realize that third-party payments, which enhance the capacity of the consumer to purchase service, do not necessarily result in the expansion of capacity of the service system. They do not guarantee maintenance of the quality of services provided or expansion of the manpower to provide them. In Medicare it would be helpful to broaden incentive reimbursement experiments, which reward those care-giving organizations that work to increase their efficiency and capacity and to lower the unit costs.

In Medicaid, the special provisions for the mentally disabled that limit compensation, in the case of persons 65 or over, to those in psychiatric hospitals are discriminatory and are not stimulating the hoped for improvements in treatment and facilities. "Maintenance of effort" regulations have proved unenforceable, and millions of dollars are flowing into State treasuries with little effect on the care of those in whose name they are claimed. These Federal funds paid under Medicaid for services to mentally disabled persons should be used (1) to stimulate more rapid development of community mental health centers and of health and mental health services for the mentally retarded and (2) to provide more humane custodial or extended care to those who need it.

All discriminatory provisions in Medicaid should be eliminated and new control mechanisms developed so that Federal payments will be directed to the benefit of those they are intended to serve. The payments could, for example, be accumulated as block grant funds for the development of new services and/or facilities for the mentally disabled.

To make Medicaid more equitable and helpful in meeting the needs of people with mental disabilities, State plans should be required to include a comprehensive program of services for such people, with emphasis on ambulatory care. Outpatient services—to include all qualified community mental health and mental retardation centers—and the provision of prescribed drugs should be mandatory. The provisions for "Maintenance of State Effort," "Interagency Planning," and "Show Progress" are all sound but need strengthening and implementation.

Rec. 25.—The Task Force recommends that all provisions discriminating against the mentally disabled be removed from Medicare and Medicaid laws, regulations, and administration; further, that the government develop and promote legislative and administrative measures to enhance the capacity of the service system.

THE IMPLICATIONS OF NATIONAL HEALTH INSURANCE

The Nation is moving rapidly towards some form of universal financing in the health care field. The Task Force endorses the basic concept of health care as a right. A problem of particular concern is the need for an insurance mechanism that deals with the problem of catastrophic illness and disability.

The Task Force is aware that numerous individuals and organizations are planning programs to redefine the responsibility of the Federal Government for the health costs of its citizens. It is important that any final program contain special provisions guaranteeing the mentally disabled access to appropriate services. Historically, special provisions in health and social insurance programs have been designed, for the most part, to deny or limit such access. In endorsing the general concept of health care as a right, the Task Force believes that this right applies to all. For this reason, services should be financed in such a way as to increase the capacity of the care-giving system. Federal officials in the agencies concerned with the mentally disabled should be encouraged to participate in planning health care insurance programs.

Rec. 26.—The Task Force recommends that the Federal Government officials most closely concerned with programs for the mentally disabled keep in close touch with the national health insurance field in order to make sure that appropriate provisions for the mentally disabled are included in any program for universal health care financing.

FINANCING—THE NEED FOR INFORMATION

The Task Force was concerned not only with the qualitative mechanisms by which financial resources are allocated among categories and among levels of government and similar matters but also with the actual dollar amounts of such funds available. There were no comprehensive collections of data available.

Rec. 27.—The Task Force recommends a special study of the total financing of programs for the disabled, including both public and private sources. A continuing mechanism should be developed so that financial data are available to program leaders at Federal, State, and local levels as well as to organizations in the private sector. These would be appropriate concerns of the Joint Council on Disabilities.

CHAPTER IX

Biomedical, Behavioral, and Educational Research

Very much more can and must be done for the mentally disabled through the improvement and expansion of services based on present knowledge and through more intensive and expanded action against social ills. At the same time, research must have high priority because it alone can offer the ultimate hope of either prevention or cure.

Research to date has been handsomely productive. It has led to measures for preventing or effectively treating certain mental illnesses having a clearly physiological origin, such as those caused by pellagra and syphilis. It has produced treatments for less clearly defined illnesses—such as schizophrenia and depression—that return many patients to full health and enable many others to function in the community. And it has been especially productive—through studies in genetics, virology, biochemistry, immunology, neurology, and prenatal and perinatal development—in showing how to prevent a number of kinds of mental retardation. Some of these were mentioned earlier.

Other types of research have pointed to factors in family life that make for mental health and others that make for mental illness; to more effective treatment for alcoholism, drug addiction, and delinquency; to means of preventing or dealing with learning problems and functional retardation; and to more effective ways of educating youngsters with mental disabilities.

The savings effected by therapeutic and preventive measures discovered through research soon outweigh expenditures. *As noted previously, when even one serious case of mental retardation is prevented, the direct savings in terms of the cost of lifetime care are more than \$100,000 and the total savings close to three-quarters of a million dollars.* And recent research is leading to the prevention of thousands of cases. In the field of mental illness, due in large part to developments in psychopharmacology, the number of patients in public institutions has been reduced from a high point of 557,000 in 1957 to 367,000 in 1969. *This decline of more than 30 percent represents an annual saving to the States of two billion dollars—five times the budget of the National Institute of Mental Health.*

The principal Federal agencies responsible for initiating, funding, and evaluating biological and educational research in the field of mental disability are the National Institute of Mental Health, the National Institute of Child Health and Human Development, and the Bureau of Education for the Handicapped.

The Task Force feels strongly that any reduction of research funds in mental health and mental retardation is false economy. It is particularly concerned for the twelve mental retardation research centers authorized under P.L. 88-164 that will come into operation in 1971. Unless these centers are funded up to the level originally estimated, they cannot achieve their full potential and much of the money spent will be wasted.

Rec. 28.—The Task Force recommends increased funds for research into the causes and treatment of mental illness and mental retardation. With respect to mental retardation, it recommends specifically that adequate support be provided for the mental retardation research centers that have already been constructed with Federal funds.

A NATIONAL LEARNING FOUNDATION

The Task Force has been especially interested in the proposal for a National Learning Foundation, made originally by the 1962 President's Panel on Mental Retardation and gaining in strength since then. The establishment of such a foundation was the prime recommendation made by the President's Committee on Mental Retardation to this Task Force and to the President. The Task Force is hopeful that the key elements of this concept will be used in planning for the recently designated National Institute of Education. Specifically, strong research efforts in the biological and behavioral aspects of learning are needed as an underpinning to the proposed educational or pedagogical activities of the National Institute of Education as it is now understood. The Institute must provide creative, bold, and unique settings in which disciplines relevant to the learning process can interact and work together.

Rec. 29.—The Task Force recommends that the Office of Education give strong attention to the issues of learning disability, the biomedical aspects of learning, and the education of the emotionally ill, mentally retarded, or otherwise disabled youngster.

EPIDEMIOLOGY AND BIOMETRICS

In discussing the functions of the recommended Joint Council on Disabilities, the Task Force has pointed to the need for biometric and

other information on the size and scope of the problem of mental disability. Funds are required for the systematic collection of data on many variables and for the development of registers and other measures that would add to knowledge and make for the more economic use of public and private funds.

Rec. 30.—The Task Force recommends that a significant increase in resources be made available for biometric and epidemiological research purposes in the field of mental disability.

CHAPTER X

Manpower, Training, and Universal Public Service

A major critical need emphasized by the officials and organizations consulted by the Task Force was manpower. The shortages are massive and at all levels, from the highly skilled professional to the newly trained indigenous worker. Since manpower shortages can never be overcome by relying exclusively on professionally trained personnel, vastly increased emphasis must be placed on "new careerists" and other types of nonprofessional workers. Concurrently, changes in training programs and curricula are needed, with emphasis on the training of personnel for the delivery of comprehensive community-based services.

If adequate facilities to cover the country are to be provided by 1980, the number of community mental health centers will have to increase from the present figure of 351 to 2,300 and community centers for the retarded from 242 to 3,000, and staff will have to be trained to man them. Additional staff will be required for the State institutions, for special education classes in the public schools, and for day care services.

In their early planning for orderly and feasible program development, the National Institute of Mental Health and the Bureau of the Budget estimated that training grant funds would need to be increased by a specific amount each year to meet the staffing needs of the community mental health and retardation centers. For a variety of reasons the actual appropriations have fallen far short of the necessary figure as estimated.

Primary Federal responsibility for the training of staff for residential and community facilities for the mentally retarded rests with the Social and Rehabilitation Service. To provide this training, the Congress, in 1963, authorized the construction of University Affiliated centers. Twenty of these have been funded so far, but a total of 60—the original goal—will be needed to meet the demand.

Unless these training facilities are fully funded, the Task Force fears the service centers already in operation and those under construction will be unable to meet their commitments because of lack of staff.

Substantial funds for the expansion of special educational services for handicapped children have been made available to the States under Titles I, III, and VI of the Elementary and Secondary Education Act,

but about 4 million of the estimated total of 6 million handicapped children are not now receiving special education. The National Advisory Committee on Handicapped Children has recommended an expansion of special educational programs but the necessary Federal funds are not available.

Rec. 31.—The Task Force recommends that funds be made available at the levels originally planned to meet the staffing needs of the mental health and mental retardation centers. It draws specific attention to the training funds administered by the National Institute of Mental Health and to those needed for the operation of the University Affiliated programs. It also draws attention to those for the training of special education personnel. Also in the area of the University Affiliated Facilities, it urges that plans be made to increase the current 20 centers to the original goal of 60.

ACADEMY OF HUMAN SERVICES

In considering means of relieving the manpower shortage, the Task Force discussed the idea of an academy of human services that would take a leadership role in developing new types of personnel and services for the mentally disabled and would prepare students for a wide variety of positions—some new in type, others conventional—in programs helping people with mental disabilities.

Perhaps eventually this "U.S. Human Services Academy" would be a central training and educational institution like the military service academies. But at least in the beginning it would operate by contractual arrangements with existing institutions, as the Peace Corps and VISTA do to meet their training needs. Among these would be colleges and universities, hospitals, and community facilities for the disabled.

The academy would make use of existing courses and programs, where appropriate, and call upon contractors to develop new ones in accordance with academy-set goals. Drawing upon pilot training programs that have already proved valuable, the academy itself might develop model courses and arrange for their use. Besides contracting for training programs, the academy could encourage other educational bodies—in particular, vocational high schools and community colleges—to offer courses preparing students for work in health-connected programs. It could also assist community mental health and retardation centers to carry out their training commitments, organize the training programs for volunteers referred to in the next chapter, and run seminars, institutes, and refresher courses for personnel in programs for the mentally disabled.

The Task Force considers this a promising idea that should be explored further.

Rec. 32.—The Task Force recommends that the President appoint a committee to consider a proposal for an academy of human services.

UNIVERSAL PUBLIC SERVICE

Concern with the manpower situation in particular and the Nation's mental health in general led the Task Force to consider universal public service, under which all American young people would give two years to their country, beginning about the age of 18. This service would be in any one of a wide variety of fields.

Though mechanisms of operation and other details are necessarily vague at this point, work settings, except for volunteers for military service, are seen as completely civilian and predominantly non-Federal: school systems, day care centers, mental health and mental retardation programs, general health facilities, community services, police, fire protection, environmental and urban renewal programs, VISTA, Peace Corps, and others.

Acceptance of universal public service involves a major shift in values, for it puts social duty on a par with military duty and requires every citizen to make a contribution to his country and himself.

Universal public service would have a tremendous impact on the manpower situation in the mental disability and other human service fields. Shortages in such areas as laboratory technicians, nurses' aides, and child care personnel would virtually disappear. And many young people exposed to public service would choose to make some facet of it their life work.

Even more important, perhaps, universal public service would enhance mental health by providing a period of social involvement, and options to military service, for *all* young people. It would attack such a disabling attitude as alienation and such a basic cause of disability as poverty.

Universal public service would also:

- enhance the skills and broaden the outlook of our youth during the critical developmental period of late adolescence and young adulthood;
- provide health and mental health screening of all young people at a given age, approximately 18, with an opportunity for remedial programming in the following two years.

The need for a careful study is evident from the size and scope of the endeavor. From 3 to 4 million people pass their eighteenth birthday in a given year. Costs, though difficult to estimate, would be in the billions. A competent and complex administrative structure will have to be set up.

Most important, the pros and cons of universal public service as against those of voluntary service will have to be weighed.

Moving the concept of universal service to reality will involve much thought, discussion and planning. The effort is worthwhile, the Task Force believes, in view of the contribution that universal service promises to the health of our society and the quality of life of our Nation.

This is, however, a controversial proposal, and several of the Task Force members strongly oppose the recommendation of mandatory universal public service.

Rec. 33.—The Task Force recommends that a Presidential committee study the desirability and feasibility of establishing a universal public service system. The basic idea to be thoroughly explored is that all Americans, probably beginning somewhere between the ages of 17 and 19, serve their country for two years in one of a variety of areas, including the military and the health and social welfare programs of the private and public sectors.

CHAPTER XI

Volunteers, Public Attitudes, and Public Education

This Nation is blessed with a treasury of volunteer talent devoting itself, or ready to devote itself, to helping people, including people with mental disabilities. Some of the talent lies in groups—notably the National Association for Retarded Children and the National Association for Mental Health—long active in programs to help people with mental disabilities. More of it lies in other organizations—because there are so many of them—dedicated to service of some kind but showing no particular interest in the needs of the mentally disabled because, mainly, no one has tried to enlist this interest. The greatest talent reserve may lie with unaffiliated individuals.

The manpower shortage, which would be even worse except for volunteers, can be further mitigated by drawing upon our reserves of talent and supplying appropriate training and supervision. It is taken for granted that volunteers will be used only when a need for personnel cannot otherwise be met.

The Task Force commends the President for his major initiatives in this area, specifically the establishment of a National Center for Voluntary Action and the accompanying Office of Voluntary Action. And it commends Mrs. Nixon for having taken on the mission of highlighting and leading a new effort in the voluntary field.

The Task Force, which has met with the staff of the National Center for Voluntary Action, welcomes the new Center and believes it will be especially productive if it takes full advantage of the knowledge and support available from organizations currently active in the volunteer field, including the National Association for Retarded Children and the National Association for Mental Health.

The following recommendation stems from the experience of Task Force members as individuals and as members of voluntary organizations.

Rec. 34.—The Task Force recommends that the national effort to increase voluntarism include provisions for determining a community's need for volunteers and for recruiting, screening, placing, training, and supervising volunteers.

RANGE OF POSSIBILITIES

The experience of one community mental health center suggests the richness of the volunteer reserve and the extent to which a major program, if knowledgeable and resourceful, can draw on it for essential services. In this center, half a dozen psychiatrists each contribute an hour a week, providing either therapy for patients or consultation for members of the staff. Several psychiatric social workers average almost a day a week apiece. The two art therapists are volunteers, as are several of the workers in the day treatment program. Among the other volunteers are a retired school psychologist; a former patient who gives 30 hours a week as an occupational therapy aide; a priest, who serves primarily as a therapist; and 25 members of the local section of the National Council of Jewish Women, who, after being trained at the center, have served as aides in the Probation Department of the Juvenile Court. Without volunteers, the center's lifestream would be reduced markedly.

Another example is a program for the severely retarded in which the Junior Women's Clubs, Boy Scouts, women in the community, teenagers, and the mentally retarded themselves are involved.

The Junior Women raised the money for a center and equipment and other women teach reading, give music lessons and provide transportation to and from the center. The Scouts run a troop for retarded boys, and the teenagers—the youth component of the Association for Retarded Children—arrange parties and outings. The mentally retarded who attend the center have supplied three hospitals and a home for the aged with bandages and bags of cotton balls; they also address and mail notices and bulletins for other community organizations.

A number of other pilot projects for demonstrating the effectiveness of volunteers in the field of mental health and retardation have been completed successfully. *The Task Force believes that the National Center for Voluntary Action can make an important contribution by collecting and publicizing details of such projects as a guide and encouragement to organizations and individuals.*

OBLIGATIONS AND CHALLENGES

The Task Force recognizes that some voluntary organizations, particularly at the local level, are eager for ideas on how to serve and would welcome concrete suggestions from groups or individuals with a special interest in the mentally ill and the mentally retarded. At the same time, the Task Force believes that any voluntary organization committed to service has an obligation to look at the country and the community and

address itself to the problems of the day. *The volunteer movement is challenged to face up to the great social problems of the times. It must understand and work with the poor and the hardcore unemployed and with people of all races. Professional workers—and agencies and institutions—are challenged also: to display a receptive attitude toward the volunteer as a fellow worker.*

Individuals, too, might well look both outward and inward and ask, "What can I do?" There is a need both for people who can offer traditional volunteer services and for people with special skills. A person who knows a foreign language, for instance, will be welcomed in many community centers and other facilities for people with a mental disability. A person who can teach remedial reading will find her services warmly accepted, particularly in programs serving disadvantaged neighborhoods. Several other areas in which volunteers could perform highly useful work are mentioned earlier on pages 27, 28, and 36.

Pre-teens and teenagers over and over have proved their worth as volunteers. Recruiters should seek them out—through schools, for instance, churches, young people's groups—because they offer vitality, creativity, and idealism. Moreover, their present value is only one reason for trying to engage them. For as they learn to help people with disabilities, some will be motivated to work permanently in one of the helping fields; others will form the backbone of the volunteer movement in the years ahead. Volunteer work might well be made part of the education-for-family-life courses advocated earlier.

TRAINING, PLACEMENT, SUPERVISION

Through every phase of the process involved in attracting and using volunteers to help people with mental disabilities, the first consideration must be quality of service, not the number of volunteers. National coordinating agencies, such as the American Association of Volunteer Services Coordinators (a professional group) and the Citizen Participation Branch of the National Institute of Mental Health (a Federal agency) emphasize not only coordination but also professional supervision and training.

The Task Force acknowledges that the very institutions which need volunteers are often unable to train them, for lack of materials and time. It proposes the preparation, for use nationally with all volunteers, of a basic manual on *working with people* and of other manuals covering particular fields of work. Such manuals would facilitate the preparation of courses; they would also make it simpler for a volunteer, wherever he or she happened to move, to describe the training received and to find

an appropriate position. These manuals and courses would not be intended to replace on-the-job training.

It is important that not only volunteers but also professional administrators and coordinators of voluntary programs receive adequate training. The shortage of such professional manpower could be overcome with a Federal Manpower and Training grant program in this area.

Volunteers make the maximum contribution when there is a carefully considered structure in which they can serve. Attention paid to the most strategic placement of a volunteer will benefit the institution or individual served as well as the volunteer himself. There are specific groups of volunteers who have special assets and corresponding needs that must be met in order to develop and enhance their services. The elderly, on fixed incomes, for example, offer a rich contribution but may need lunches, transportation, and incidental expenses paid for. The same may be true of young people, particularly the pre-teens and the teens. The provision of expense money may enable numerous individuals outside of these groups to serve where needed.

In addition to being trained and supervised, the Task Force feels that volunteers need to be, and *deserved* to be, evaluated at least once a year. Volunteers who have proved themselves ought to be able to move upward, in terms of using additional skills and bearing additional responsibility.

NEW USES, AND OTHER NEEDS

The Task Force sees these other needs:

- A search for and an awareness of important new ways in which volunteers can be used. One such role might be that of *emotional guardian* for the elderly. Another important role, especially in terms of preventing mental disability, would be that of *big sister* or *big brother* in a college or a high school. Here the more mature, more sophisticated student would put an arm around a less mature, socially uncomfortable fellow student and help ease his way through difficulties that too often result in adolescents' suicide.
- The recruitment of more men for work as volunteers.
- Recognition of the volunteer work being performed by patients and former patients, and an effort to use these workers more extensively.
- Wider use of other than middle-class persons as volunteers.
- The recruitment of returning Peace Corps and VISTA workers.
- Wider use in community-based facilities of qualified coordinators of volunteer services.

- Greater recognition that voluntarism is a two-way street. Participation in worthwhile services enhances both the volunteer's competence and sense of worth. Voluntarism can truly be a contribution to the individual's own mental health.

INFLUENCE ON THE PUBLIC

The volunteer potential ranges from a direct service—a one-to-one contribution to the quality of life of a mentally disabled person—to a major collective contribution by individuals acting in concert to improve public or private programs in the field of mental health and mental retardation. The volunteer effort can be a vital addition to community resources and to community plans. Further, volunteers have the power—perhaps more of it than any other group except teachers—to encourage the development of healthy attitudes toward mental illness and mental retardation.

For example, plans for the wider acceptance of disturbed or retarded children into Boy Scout or Girl Scout organizations and into the swimming programs of the Red Cross might well lead to a dramatic advance in the public attitude toward people with mental disabilities.

PUBLIC ATTITUDES AND PUBLIC EDUCATION

The public attitude towards mental illness and mental retardation is a vital factor in determining the quality and the extent of efforts in this field. It is the strongest force among those shaping the financial and other resources made available to deal with the problem of mental disability. It determines the locale of care—the local community or the distant, isolated facility—and the amount of money available for that care, for other services, and for research. And it plays a subtle, critical role through the operation of a powerful, self-fulfilling prophecy. If the public attitude is supportive towards the mental patient returning home from the hospital, or to the retarded person in a special class at school, that individual has a far greater chance to succeed in personal, social, and vocational adjustment than if the public attitude is hostile or rejecting. Further, public attitudes towards larger social issues such as prejudice, violence, and poverty may play an enormous role in the actual mental health of our society.

Healthier attitudes beget better programs, and more of them; better programs lead to healthier attitudes. The progress of the community mental health center movement, of programs for the mentally retarded,

and of research into the causes, treatment, and prevention of mental disability are good evidence that public attitudes have been growing healthier. The unmet needs recounted in this report—unmet in spite of the increasing knowledge of how to meet them—are good evidence that the change must be continued and accelerated.

Other factors, too, are highly important in the changing and molding of public attitude—chief among them, planned information and public education programs by groups of parents and other voluntary organizations. The Task Force reviewed and commended the extensive efforts over the years of the National Association for Mental Health, the National Association for Retarded Children, the Junior Chamber of Commerce, the National Urban League, the Family Service Association of America, the Junior League, the National Advertising Council, and other agencies and individuals.

The task for further improving the public attitude toward mental disability is a large one, but those concerned have many actual or potential resources and can call upon research findings in the social sciences and the technology of mass communication to help exploit them.

Rec. 35.—The Task Force recommends that each of the committees of the Joint Council on Disabilities review the subject of public attitude. The Joint Council should then recommend overall policy for improving the public attitude toward mental illness, mental retardation, and physical disability.